

Illinois Parents of Adults with Developmental Disabilities Unite is a group of 1,200 parents and other concerned people that has operated a statewide Yahoo listserv for the past seven years.

IPADDUnite offers the following recommendations in response to the State 1115 Draft Waiver Concept Paper (DWCP), section titled Pathway #1: Home and Community Based Infrastructure, Coordination and Choice:

The DWCP states:

Rationalize service arrays and choices so that they are based on beneficiary needs and preferences to remain as independent as possible, rather than disability or condition. Develop a universal assessment tool (UAT) for Seniors and Persons with Disabilities that will support efforts to tie services to the needs of the beneficiary.

IPADDUnite responds:

- * Adopt objective assessment tools that cross all waiver categories, for all individuals--one that measures ability to perform Activities of Daily Living and another that takes into account the real (geographic or regional) costs of care to the individual, their family and caregivers, including community service providers.

- * Adopt a flexible "continuum" funding model versus a fixed funding allocation for all, that reflects real support and service costs for each individual and that is directly tied to objective assessment tools. Based on individual support needs, some will receive higher waiver allocations than at present and others will receive lower allocations. Additionally, individual needs will change as people age -- some will need more support, others potentially less, and the Waiver should be flexible enough to respond to these changing needs, as documented.

- *Eliminate the current I/DD PUNS waiting list and replace it with one that is transparent and that measures the real need of individuals and their families for services and supports.

DWCP: Reduce waiting lists for waiver services.

IPADDUnite responds:

*Develop objective and achievable goals to eliminate the waiting lists for services altogether within five years, as many other states have done.

*Resume selection of children from the I/DD waiting list for supports and services, which has not been done for more than three years

DWCP: Reduce administrative complexity and cost inherent in managing nine separate waivers.

IPADDUnite responds:

*Retain and empower the Department of Human Services, Division of Developmental Disabilities, as the single point of entry and administrator of the service delivery system for individuals with I/DD.

DWCP: Provide the flexibility needed to deliver appropriate and essential HCBS waiver services, also referred to as "long-term supports and services" (LTSS), in a coordinated fashion through managed care entities and their provider networks.

IPADDUnite responds:

*Exclude the Intellectual and Developmental Disability population from Managed Care, which has been demonstrated in many other states to not be appropriate for this population.

DWCP: Increase flexibility and choice for beneficiaries.

IPADDUnite responds:

*Prioritize community employment and funding support that responds to the individual's specific needs in acquiring, maintaining and retaining long-term employment.

*Incentivize expansion of approved day programming options beyond large, congregate developmental training centers to allow individual access to community employment, microenterprise or volunteer opportunities, hobbies, shared interests, and social interactions.

*Incentivize and expand an array of smaller, more individualized models of residential living that afford a person with disabilities choices in how, where, and with whom their needs are met.

*Encourage development of creative community living supports such as microboards and cooperatives, increasing opportunities for self-direction and building personal support networks within the community-at-large.

*Implement individualized rate models for the I/DD Home-Based Services Program and day services that base funding levels on need rather than the current one-size-fits-all systems.

DWCP: Develop outcome-based reimbursement strategies that emphasize quality of care and align payments with the goals of the program.

IPADDUnite responds:

*Include the same points under "Pathway #1: Home and Community Based Infrastructure, Coordination and Choice" that appear under "Pathway #2: Delivery System Transformation" applying to hospitals and nursing homes, as follows:

Development and implementation of an incentive-based pool for I/DD Home and Community Based service providers to drive transformation, including, but not limited to:

--Quality of care improvements;

--Development, implementation and training on effective transitions of care models between nursing facilities, ICFDDs and home and community-based care;

--Debt relief or capital investment for I/DD providers that commit to transforming, redesigning, downsizing or closing some or all of their facilities, including technical assistance in developing new business models to retool facilities to meet the needs of emerging populations;

- -Flexibility to develop and fund additional, creative, and individualized supportive housing and employment options at the appropriate levels.

*Empower and assist community provider agencies to fulfill their mission:

--Establish adequate reimbursement rates in line with the rest of the nation.

--Ensure prompt reimbursement.

--Ensure adequate funding for additional staffing in cases of behavioral or medical challenges.

--Create a crisis system that does not rely on state-operated facilities.

These recommendations were drafted by IPADDUnite leaders Laurie Jerue and Ellen Garber Bronfeld with assistance from Helen Kauffman, Bonnie Dohogne, Vicki Niswander, and Ed McManus. For further information, contact Ellen at 847-212-3036.

Thank you.

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